ASSESSMENT OF HEALTH-RELATED QUALITY OF LIFE (HRQOL) IN ADULTS WITH AUTISM

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Autism spectrum disorders (or collectively known as “autism”) are a group of developmental disorders that are associated with limitations in social interaction, communication, and repetitive behavior. Autistic disorder, Asperger’s syndrome, and pervasive developmental disorder-not otherwise specified (PDD-NOS) fall under the umbrella term autism. A recent report by the Centers for Disease Control and Prevention (CDC) indicated the prevalence of autism to be 1 in 68 among children aged 8 years in the United States (US) (1). Prevalence among boys is reported to be ~5 times higher as compared to girls. Despite the increasing prevalence of autism over the past few decades, we still do not completely understand the underlying reason that leads to its occurrence. However, it is known that combination of genetic and environmental factors play a role in the occurrence of autism.

Focus of most of the research in autism has been on children, with little attention given to adults living with the disorder. Autism is a chronic disorder that cannot be cured. Though there are treatments available that can help in symptom management, a full cure for this disorder still does not exist. As a result, adults with autism not only experience limitations associated with the disorder, but also have to face typical challenges associated with adulthood under the prism of the disorder. Poor health among adults with autism could impose daily challenges, and add to the burden of autism. When reviewing the literature on adults with
autism, we realized that there were no studies that had assessed health-related quality of life (HRQOL) among adults with autism in the US. HRQOL basically represents the physical, psychological, and social health of an individual. Research has shown that poor HRQOL can lead to early mortality and greater use of healthcare resources (2-6). A few studies have assessed HRQOL among adults with autism (7-10), but all have been conducted outside of the US.

We therefore conducted a study of adults with autism in the US to determine their HRQOL. In order to do so, we used a survey measure, i.e., Medical Outcomes Study Short-Form Health Survey version 2 (SF-12v2) (11), which is commonly used to assess HRQOL.

We aimed to identify the factors that influence HRQOL among adults with autism. We wanted to see if socio-demographic factors (age, gender, race, insurance status, occupation, education, marital status), general health (other physical and mental illness), use of autism-related treatment, age when diagnosed with autism, social support, coping, and autism severity had an influence on HRQOL. Since the SF-12v2 had not been previously used to assess HRQOL among adults with autism in the US, we also aimed to test the reliability and validity of this measure in this population. Reliability means that the same result will be obtained time and again if we were to use the same measure (SF-12v2) in the same study population (adults with autism). Validity means that the measure (SF-12v2) actually assesses HRQOL and not some other factor. A good measure is both reliable and valid.

To conduct our study, we approached adults with autism (18 years and above) who were registered with the Interactive Autism Network (IAN). An online survey of adults with autism was conducted to collect data needed for the study. An email with study information and survey link was mailed to adults with autism. To protect the identity of these participants,
the email was mailed directly by the IAN. Before conducting the study, we received approval from the University of Mississippi Institutional Review Board.

A total of 291 valid responses were received for our online survey. On average, our survey participants were 30 years of age. Most (80%) were White, and three-fifths were male. Male adults with autism had lower mental health across all age groups as compared to male adults in the US population (Figure 1). Male adults with autism also had lower physical health among age groups 25-34 years and 55-64 years as compared to male adults in the US population (Figure 1). Female adults with autism in our survey had lower mental health among age groups (18-54 years) as compared to female adults in the US population (Figure 2). We found that adults with autism (males and females) without any other mental illness also had lower mental health as compared to adults in the US population (Figure 3). This highlights that the physical and mental health of adults with autism is poorer as compared to their peers with typical development in the US population. Autism not only places neurodevelopmental limitations, it also is associated with poor health among adults with the disorder.

We also found that social support and coping had a significant influence on the physical and mental health of adults with autism who participated in our survey. The use of maladaptive coping, i.e., negative techniques such as denial, self-blame, behavioral disengagement, venting to deal with issues associated with autism, was associated with poor physical and mental health among adults with autism. Adults with autism who had higher social support (from family and friends) had better physical and mental health. Other socio-demographic factors (marital status, insurance status) and presence of other disorders also had an influence on physical and mental health of adults with autism. However, coping and social support consistently emerged significant factors influencing both physical and mental health of adults with autism. Social
support is important for all individuals, but they have a particularly important role among adults with autism. Family members, friends, and support providers should strengthen the social support provided to adults with autism. As per coping, adults with autism should be taught positive coping techniques such as humor, use of emotional support, planning, etc. to deal with the stresses placed by autism on their daily lives. Use of negative coping techniques could have a bad influence on their physical and mental health.

When examining the reliability and validity of the SF-12v2, we found this survey measure to work well among adults with autism. That means, future researchers who wish to use SF-12v2 to assess HRQOL among adults with autism could do so with good degree of confidence.

The key findings of this study therefore were the lower physical and mental health among adults with autism as compared to adults in the US population, and the role of coping and social support in influencing the health of adults with autism. Clinicians and other professionals involved in autism management among adults with autism should consider assessing both physical and mental health of these individuals on a regular basis. Further, support services provided to adults with autism should incorporate elements of both positive coping techniques and social support provision. This is the first such study in the US that assessed the physical and mental health of adults with autism. Further research is needed to understand the long-term health impact among this population. With increasing prevalence of autism, the number of adults with autism is likely to increase in the coming years. Policy makers should consider providing health interventions to adults with autism on a regular basis, with the aim of improving their physical and mental health.
The authors of this study are truly grateful to adults with autism who participated in the study. The authors would like to thank the Organization for Autism Research (OAR) for providing the funding for this study. Without the OAR funding, this research study would not have been possible.
References


Figure 1: Comparison of mean HRQOL scores among males adult with autism to general US population norms

*P≤0.001; **P≤0.05
Figure 2: Comparison of mean HRQOL scores among females adult with autism to general US population norms

*P≤0.001; **P≤0.05
Figure 3: Comparison of mean MCS scores among adults with autism (without other mental illness) to general US population norms

Sample mean

US Population norms

*P≤0.001